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ABSTRACT

A survey was conducted to determine states' progress towards developing a definition for developmentally delayed infants and toddlers as required by Public Law 99-457, Part H. Results of the survey, conducted in the summer of 1988, indicated that many states had made a great deal of progress toward developing a policy regarding the definition of developmentally delayed, most states had only partially completed the process, and a few had not yet begun. The Interagency Coordinating Council and the lead agency were identified as playing a major role in providing input into this process. A content analysis of the completed definitions from 28 states showed that all definitions included developmentally delayed infants and toddlers and those with established risk. Three major types of eligibility criteria were prominent: percent delay, delay in number of months, and delay as indicated by standard deviation. Within these major areas, there was considerable variance in the level of delay needed to establish eligibility for services. Over half of the states included at-risk infants and toddlers, but there was minimal agreement as to which factors place a child at risk, with 53 different biological criteria and 36 environmental risk factors being cited by states using these categories in forming definitions. (JDD)

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Carolina Institute for Child and Family Policy

STATUS OF THE STATES' PROGRESS TOWARD DEVELOPING A DEFINITION FOR DEVELOPMENTALLY DELAYED AS REQUIRED BY PL 99-457, PART H

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EXECUTIVE SUMMARY

This study was conducted by the Carolina Policy Studies Program to determine the progress across the 50 states and the District of Columbia towards developing a definition for developmentally delayed infants and toddlers as required by PL 99-457, Part H. A telephone survey was conducted in the summer of 1988. One purpose of the survey was to determine the current status of the policy development process in defining the population to be eligible for services under PL 99-457, Part H. Another goal was to obtain a description of the policy development and approval process to be used.

Results of the telephone survey indicated that many states had made a great deal of progress toward developing a policy regarding the definition of developmentally delayed. However, most states had only partially completed the policy development process, while a few had not yet begun the process. There appears to be broad-based participation in the policy development and review process. The Interagency Coordinating Council (ICC) and the lead agency were identified as playing a major role in providing input into this process. Some states indicated that they were conducting impact research to aid in policy development. Once the policy is developed, it must be approved. The ICC appears to be the agency most frequently mentioned as providing final approval, however, the legislature, lead agency, and the governor were frequently cited, as well.

During the telephone survey, twenty-eight states indicated that they had developed a definition for developmentally delayed. A content analysis was done on all 28 definitions. All the definitions included developmentally delayed infants and toddlers and those with established risk. Although the definitions closely mirrored the language of PL 99-457, Part H, they varied greatly when the eligibility criteria were examined and compared. Of the states who included criteria, 3 major types were prominent: (a) percent delay; (b) delay in number of months; and (c) delay as indicated by standard deviation.

Within these major areas, there is considerable variance in the level of delay needed to be eligible. For example, those states' definitions using percent delay, utilized percentages ranging from 20% to 50% delay in one or more areas and from 15% to 25% in two or more areas. Those using standard deviations and months delayed also varied greatly. From this analyses, it appears that most states are relying heavily on a psychometric approach for determining eligibility. This is somewhat troubling, since many states have indicated they are using percent delay or months delay which is incompatible with the scores derived from many of the assessment instruments currently used.

At this point, it appears that over half of the states analyzed have taken advantage of the opportunity to include at-risk infants and toddlers. The analysis revealed that there appears to be a heavy reliance on the single factor approach to determining risk. In addition, there appears to be minimal agreement as to which factors place a child at-risk. An analysis of the 17 states which included biologically

at-risk infants and toddlers revealed 53 different criteria. Thirty-six different criteria were listed by the 16 states which included environmental risk factors. It would appear from the current content analysis of definitions that there are substantial differences among states as to which infants and toddlers will be served under PL 99-457, Part H.

The federal government through the passage of PL 99-457 has provided an impetus for states to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with developmental delays and their families. This legislation is based upon a growing body of literature concerning the importance of early intervention for infants and toddlers with handicaps, as well as those who are at-risk of developing handicapping conditions. Consequently, states choosing to participate in this federal program are required to provide early intervention services to developmentally delayed children and children with conditions which lead almost invariably to developmental delays (e.g. Down Syndrome, Cerebral Palsy). In addition, states may choose to serve children who are "at-risk" for developmental delays.

The federal government, as part of this monumental legislation, has charged the states with developing a definition for developmental delay and designing an appropriate service delivery system. This definition, to be developed by each participating state, is only one of the fourteen components of a service delivery system required by PL 99-457, Part H (see Table 1). However, it is an extremely pivotal component, because decisions concerning the nature of the other thirteen components will depend partially upon this definition. For example, before state policymakers can adequately design and implement a Child Find system (one of the required 14 components) a decision must be made concerning the children who will be served. In addition to a "definition", state policymakers must also decide what criteria will be used to determine the child's eligibility for services.

Table 1: Minimum components of PL 99-457, Part H

1. Definition of developmentally delayed
2. Timetable for serving all in need in the state
3. Comprehensive multidisciplinary evaluation of needs of children and families
4. Individualized family service plan and case management services
5. Child find and referral system
6. Public awareness
7. Central directory of services, resources, experts, research and demonstration projects.
8. Comprehensive system of personnel development
9. Single line of authority in a lead agency designated or established by the governor for implementation of:
   a. general administration and supervision
   b. identification and coordination of all available resources
   c. assignment of financial responsibility to the appropriate agency
   d. procedures to ensure the provision of services and to resolve intra- and interagency disputes
   e. entry into formal interagency agreements
10. Policy pertaining to contracting or making arrangements with local service providers
11. Procedure for timely reimbursement of funds
12. Procedural safeguards
13. Policies and procedures for personnel standards
14. System for compiling data on the early intervention programs

While there is widespread consensus concerning the need for early identification and early intervention for infants and toddlers with handicapping conditions, the task confronting policymakers to define the population to be served and develop adequate procedures to identify eligible children is a difficult one. This task is made difficult by a variety of factors. First, the nature of infants' and toddlers' development often makes it difficult to determine the existence of a problem (O'Donnell, 1989; Simeonsson & Bailey, 1989). The areas of development (e.g. cognition, motor, etc.) are interdependent and interact in very complex ways (Emde, 1981).

Second, the ability of assessment instruments to predict child outcome beyond three years of age is limited (McCall, 1982). Third, there is an absence of reliable data concerning the actual number of children in question. Estimates vary depending on how narrow or broad the definition of "handicapped" and whether at-risk children are included. Estimates range from 1 percent to 12 percent for preschoolers with handicaps (Fraas, 1986). When at-risk children are included, the percentage may go up to 20-30% depending upon whether the definition is narrow or inclusive.

Fourth, the existing professional literature provides relatively little guidance as to which risk factors most probably result in delays or disabilities. The literature has been somewhat useful in providing information concerning isolated conditions and single risk factors. The major limitation of this approach is that handicapping, or potentially handicapping, conditions frequently do not appear in isolation. Rather, combinations of handicapping conditions or syndromes are common (e.g. low birth weight, intraventricular hemorrhage, and a diagnosis of

cerebral palsy). Consequently, models which have attempted to predict future functioning (e.g. school performance) on the basis of a single risk factor such as anoxia or intraventricular hemorrhage have been of limited usefulness because of their high error rates (Kochanek, Kabacoff, & Lipsitt, 1987).

Finally, most states are faced with reconciling the requirements in PL 99-457, Part H with eligibility policies which existed prior to the passage of this federal legislation. Further complicating this issue is the fact that in many states there were (and still are) eligibility criteria developed by various agencies, which are often based upon a variety of other federal legislation (e.g. Early Periodic Screening, Diagnosis and Treatment; Developmental Disabilities; Public Law 94-142; Headstart; Children's Special Health Care Services). All too often these federal laws have conflicting or overlapping eligibility criteria (Harbin & McNulty, in press). The development of a coordinated policy concerning who is eligible for services is a major challenge to state policymakers. Although the task facing state policymakers is difficult and complex, with a relatively limited information base to assist them, there appears to be a strong, broad-based commitment from parents, professionals and state policymakers to improve and increase services to children and families who need early intervention services. (Smith & Strain, 1988).

PURPOSE OF STUDY

The purpose of this study was to determine the current progress across states towards developing a definition for <u>developmentally delayed</u> as required by PL 99-457, Part H. In addition, the study sought

to analyze the content of these definitions and to identify issues and potential consequences raised by the current definitions. This is an ongoing study within the Carolina Policy Studies Program. Therefore, this is the first report in a series of policy analysis studies concerning the development of a definition of developmentally delayed as required in PL 99-457, Part H.

METHOD

This study contains two components: (1) a telephone survey of all 50 states plus the District of Columbia concerning the status of the development of a policy related to defining developmentally delayed and a description of the policy development and approval process to be used; (2) a content analysis of the definition policy, developed to comply with the requirements of PL 99-457, Part H.

Survey

A telephone survey instrument was developed based upon results from previous surveys concerning policies in this area (Meisels, Harbin, Modigliani, & Olson, 1988; Walsh, Campbell,& McKenna, 1988; Gallagher, Harbin, Thomas, Wenger, & Clifford, 1988). Five CPSP staff members conducted interviews with the Part H Coordinator in all 50 states plus the District of Columbia. The Part H Coordinator was called by a CPSP interviewer to explain the purpose of the survey and to schedule an appointment for the telephone survey. Each survey respondent was told that the telephone survey would last approximately 30 minutes.

Prior to conducting the telephone survey, the CPSP interviewers reviewed the questions together, discussing the purpose of each question, as well as probes to use if needed, in order to obtain a more

complete answer to the question or to clarify the answer. Due to the crowded and busy schedules of the Part H Coordinators, telephone surveys were conducted between May and August, 1988. All 50 states plus the District of Columbia agreed to participate and were extremely cooperative. The telephone surveys ranged from 30 minutes to 90 minutes in length.

The same survey protocol was used by all interviewers for all states. Results of the surveys were reviewed and coded by only one of the interviewers. If there was some question about the clarity or accuracy of an answer, the first step was to discuss it with the CPSP interviewer in order to obtain clarification. If that proved unsuccessful, the Part H Coordinator for the state in question was called.

Policy Analysis

In the telephone survey, described above, 27 states indicated that they had developed a definition to comply with PL 99-457, Part H. These 27 states were asked to send their definitions to be analyzed. While waiting for the states to send in their definitions, 1 additional state developed a draft definition. Thus, as of November, 1988, 28 states had developed a definition and sent it to CPSP for analysis. It is important to note that these 28 definitions varied considerably in their level of completion. A few were described as approved policies. While others had been approved by the Interagency Coordinating Council (ICC), but had not been approved by a state official. Still others were drafts which were still under discussion by the ICC.

The content analysis of the 28 definitions addressed the following: (a) was the definition categorical, non categorical, or some

combination; (b) what were the criteria used to determine delay; (c) did the definitions include a category for atypical development; (d) did the definitions include biologically and/or environmentally at-risk, and what criteria were delineated for each at-risk group. In order to check the reliability of the analysis, a sample of 50% of the definitions was analyzed by someone outside of CPSP - Dr. S. Gray Garwood, who was formerly the Director of the House Subcommittee on Select Education and very instrumental in both the development and passage of PL 99-457. There was 100% agreement for all state definitions in the reliability sample.

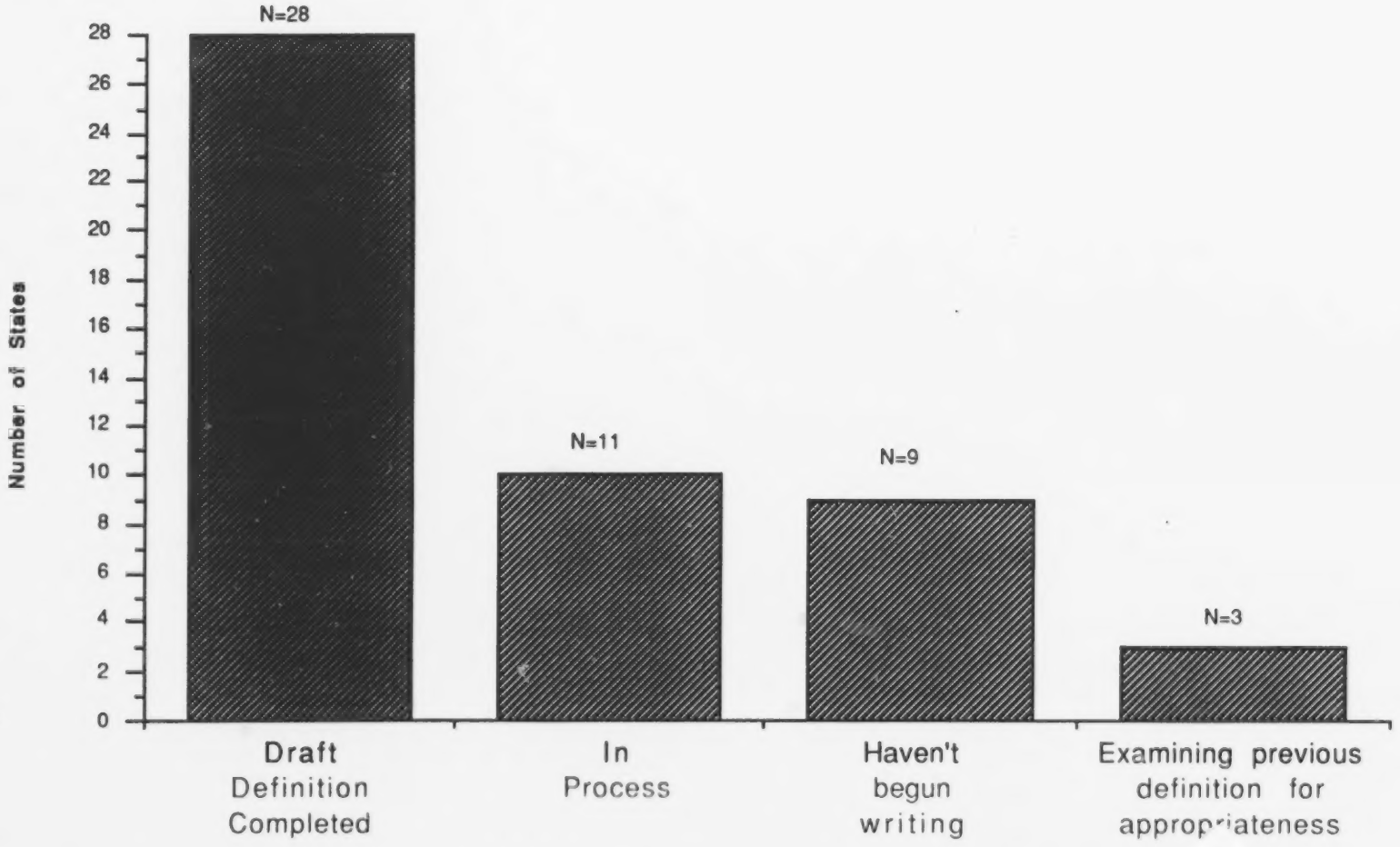
RESULTS

What Is The Status Of The Definition?

Prior to the passage of PL 99-457, definitions concerning who was eligible for services varied greatly among states (Gallagher, Harbin, Thomas, Wenger, & Clifford, 1988). According to survey results for this current study, 28 states have written a definition which meets the requirements of Public Law 99-457 (see Figure 1). These 28 definitions, however, vary in their stages of completion. A few states have finalized their drafts, while the definitions for other states are still in draft status and under review.

Of the remaining 23 states, 11 were in the process of writing a draft definition and 3 were examining previous definitions for their appropriateness. In many instances, these states are currently using a task force to gather information and develop a draft definition. Finally, there were 9 states that have not begun to write a draft definition.

Figure 1: STATUS OF DEFINITION
Part H, P. L. 99-457



However, several of the states in this category are using a data-based approach to developing the definition. Some states using a data-based approach have designed systematic studies to provide data concerning the number and type of children potentially eligible. Other states are using pilots to compare various definitions.

Who Is Included In the Definition?

PL 99-457, Part H requires each participating state to serve infants and toddlers from birth through age 2 who "are experiencing developmental delays" or "have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay", (Education of the Handicapped Act Amendments of 1986, Section 672 [1])referred to by many professionals as established risk. At the state's discretion, infants and toddlers "who are at-risk of having substantial developmental delays if early intervention services are not provided" (Education of the Handicapped Act Amendment of 1986, Section 672, [1]) may also be included in the definition.

Figure 2 indicates that of the 28 definitions analyzed, all 28 states were including developmentally delayed children and children with established risk. There were 17 states who had included children with biological factors which place them at-risk (e.g. intraventricular hemorrhage, low birth weight, etc.). There were 16 states who included children with environmental factors which place them at-risk (e.g. developmentally disabled parent, mother with history of substance abuse, poverty, teenage mother). There were 2 states who included children placed at-risk due to environment, but the state's definition did not include biologically at-risk infants and toddlers. There were 3

states who included biologically at-risk but not environmentally at-risk children, and 14 states who included both biologically and environmentally at-risk. Thus, 82% of the states that include children at-risk, incorporate both biological and environmental risk factors.

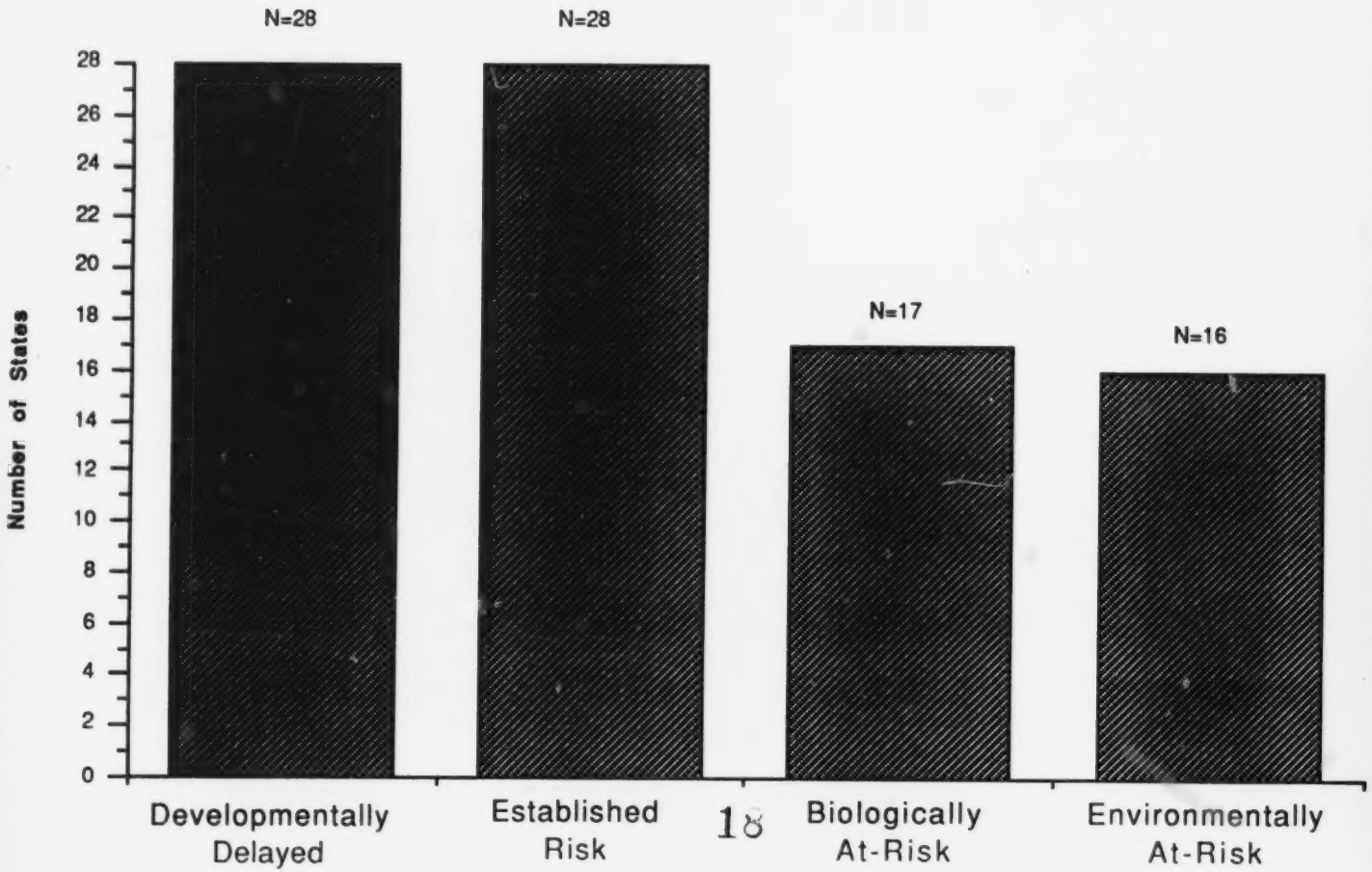
It remains to be seen whether any of the states that have not yet begun or have just begun to write their definition will address the optional at-risk conditions. Since many of the current definitions have not yet been finalized, it is also possible that some states, might decide not to include children at-risk prior to final approval of the definition.

An analysis of the 28 definitions currently available, indicated that some states had included an additional category called "atypical development". In this category, observable behaviors are used to determine eligibility (e.g. diagnosed hyperactivity, inadequate or disturbed social relatedness, excessively aggressive behavior, and disturbed eating or sleeping patterns).

Does The Definition Include Criteria To Determine Developmental Delay?

Once state policymakers have written a definition, there must be some way of determining just which children fit the definition and are eligible for services. The question facing states is how delayed must a child be in order to receive services. In many instances, the development of the eligibility criteria for services raises controversial issues as well. The lack of adequate instruments and research in this area makes policy development problematic and difficult (Harbin, in press; Simeonsson & Bailey, 1989). An analysis of

Figure 2: WHO IS INCLUDED IN DEFINITION (28 STATES REPORTING)



the 28 definitions reveals that eligibility criteria to determine developmental delay varies greatly among the states.

Figure 3 reports the results of the content analysis of the 28 definitions. There were 7 states who included no criteria in order to determine delay. One of these states had a policy that the eligibility criteria was to be determined locally. It may be the case that the other 6 states who did not include criteria, either had not yet had a chance to develop the criteria, or intended for the criteria to be locally determined. In this case, eligibility for services is likely to vary based upon where the child resides.

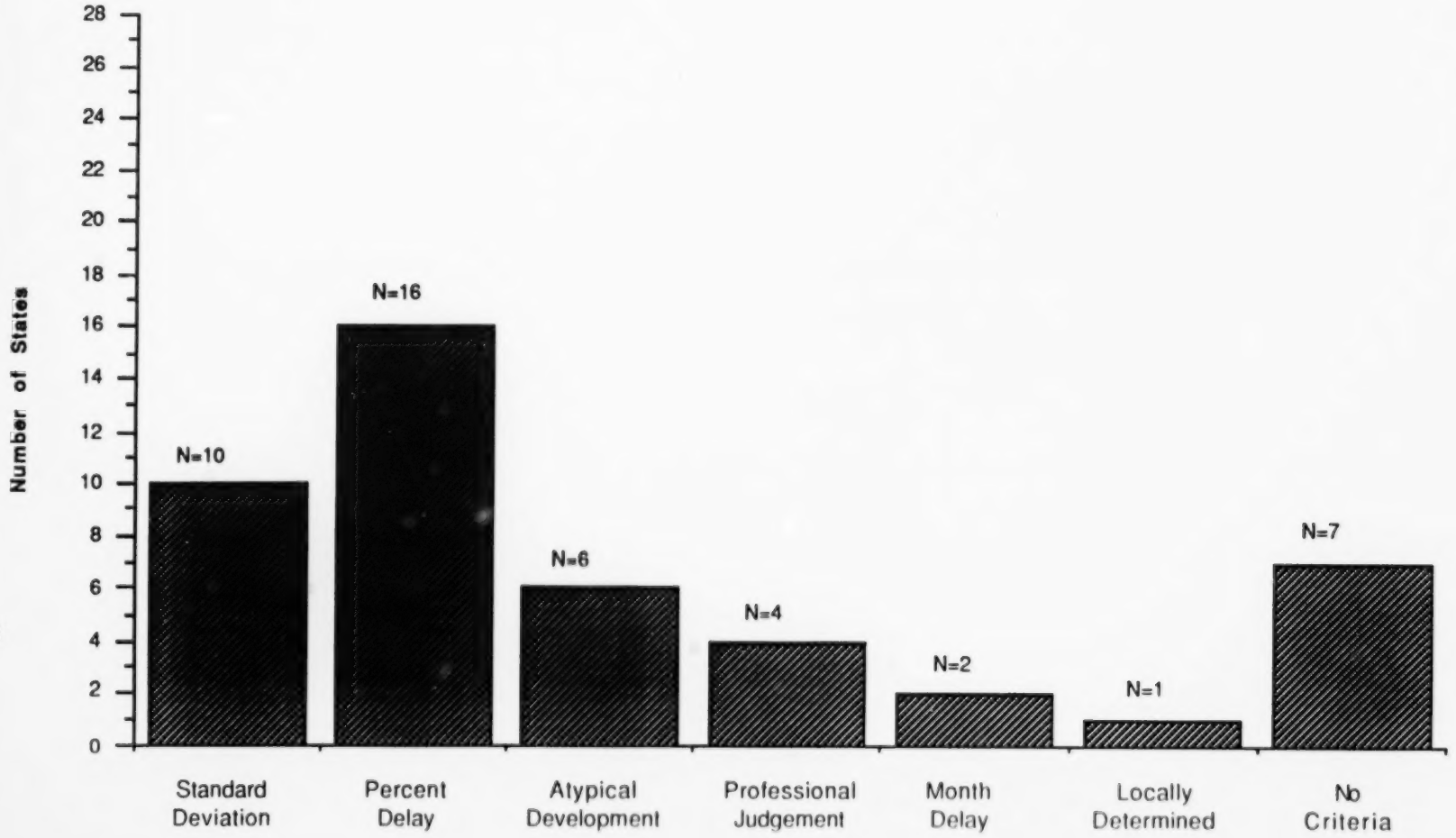
An examination of the criteria used by the 21 states who did include eligibility criteria indicated five major types:

percent delay;
delay in number of months;
delay as indicated by standard deviation;
delay indicated by atypical development in observable behaviors and/or characteristics; and
professional judgement.

In most definitions which include criteria, some combination of these five types of criteria was used to establish delay (e.g. standard deviations and percent delay or standard deviation and professional judgement). It should also be noted that for the most part, the eligibility criteria used will require the use of standardized assessment instruments.

A major finding in the analysis was that there is considerable variance among state definitions in the level of delay needed to be eligible. Those state definitions using a percent delay, utilized

Figure 3: TYPES OF CRITERIA TO DETERMINE DEVELOPMENTAL DELAY (28 States Reporting)



percentages ranging from 20% to 50% delay in one or more areas of development, and from 15% to 25% in two or more areas of development.

Percentage of Delay Used to Determine Developmental Delay

Percent delay	Number of areas	Number of states
15%	1 or more	2
15%	2 or more	2
20%	1 or more	3
25%	1 or more	6
25%	2 or more	2
40%	1 or more	1
50%	1 or more	1

Several state definitions determined delay by using standard deviation. These criteria also varied greatly:

Levels of Standard Deviation Used to Determine Developmental Delay

Standard deviation	Number of areas	Number of states
1.5	1 or more	6
1.5	overall development	1
1.5	2 or more	1
1.0	2 or more	1
1.0	3 or more	1
2.0	1 area	1
2.0	In motor (under 18 mo.)	1

Those state definitions using months delay varied as well. Some used a six month delay in two or more areas. One state definition used a three to eighteen month delay in one or more areas with the range of

delay (3-18 months) attributed to level of severity. A few state definitions used a range of three to nine months delay in one area of development, with the number of months delay increasing with the age of the child (e.g. 1 year of age - 3 months delayed, 2 years of age - 6 months delayed).

The most frequently used criteria were the 25% delay in one or more areas of development (N=6) and 1.5 standard deviations in one or more areas of development (N=6). While most of the definitions include some criteria to determine delay, the diversity and range of criteria used will undoubtedly affect who will be eligible for services from state to state.

What Criteria Are Used To Determine At-Risk?

If the state decides to include children who are at-risk of delayed development, policymakers are compelled to determine which factors render which children at-risk (Smith & Strain, 1988).

Biological Risk. An analysis of the criteria selected by the 17 states for placing children at-risk due to a biological condition revealed that states have listed 53 different criteria. Table 4 presents the range of criteria being used. The analysis also indicated that there is relatively little agreement among states as to which factors place children at-risk. There were 24 factors which were selected by only 1 state. There were 26 factors which were selected by 2-4 states, and only 2 factors selected by five or more states. At the present time there appears to be minimal agreement among states concerning which factors place a child at-risk biologically.

Table 4: Biological Risk Factors Selected by States

Factors Selected by One State	Factors Selected by Two or More States
low birthweight	Tjossem/broad definition (6)
infectious illness	premature < 32 weeks (5)
birthweight < 2500 grams	birth trauma/infection/disease (4)
traumatic illness/acute event	chromosomal abnormalities (4)
apgar < 6 at 5 minutes	sensory impairments (4)
failure to thrive	low birthweight < 1000 grams (3)
neonatal ICU > 30 days	birthweight < 1500 grams (3)
neonatal intensive care > 7 days	mother exposed to medications known to cause brain damage (3)
ventilator support > 48 hours	neonatal seizures (3)
ventilator dependent	established risk factors (3)
respirator distress with prolonged mechanical ventilation	small for gestational age (3)
neurological complications	metabolic disorders (3)
diabetic mother	lead poisoning/toxins (3)
abnormal neurological exam	congenital abnormalities/syndromes (3)
exposure to teratogens/drugs which cause brain damage	complications at birth (3)
history of mental illness	premature (2)
intraventricular hemorrhage grade III/IV	prematurity with complications (2)
atypical developmental patterns	chemically dependent mother (2)
parental age	abnormalities in tone (2)
parental health problem	serious accident/near drowning (2)
feeding dysfunction	asphyxia with neurological complications (2)
delay/abnormal motor patterns	history of substance abuse (2)
unusual sleep patterns	congenital infections/neonatal meningitis (2)
pregnancy complications	infant/toddler acquired postnatal complications (2)
	growth deficiency/nutritional problems (2)
	significant medical problems (2)
	chronic otitis media (2)
	prenatal infections (CMV, rubella, AIDS) (2)

*( ) number of states which included the factor

The analysis of the definitions also revealed that there is confusion and lack of agreement concerning what is considered to be established risk and what is considered a biological risk. For example, some state definitions combined the two categories and labeled it established risk. Other state definitions include under biological risk, conditions which are often included under established risk (e.g. chromosomal abnormalities) and vice versa.

In many instances while state definitions included a list of criteria to determine eligibility for children at-risk, these definitions also included the phrase "but is not limited to the following". The use of this phrase leaves flexibility for other factors or conditions to be accepted for eligibility. It is possible that this flexibility in the policy will result in even more diversity of interpretation of eligibility.

Finally, all seventeen states used a single factor approach to determining eligibility for children with biological risk factors. That is, in order to be eligible for services, an infant or toddler would need to have only one of the factors listed on the checklist (e.g. prematurity). Unfortunately, the limited usefulness of single risk factors in predicting which children are likely to develop delays or disabilities has been noted earlier in this paper and is documented in the literature (Kochanek, et al, 1987).

Environmental Risk. An analysis of the criteria selected by 16 states for placing infants and toddlers at-risk due to environmental conditions revealed that states have listed 36 different criteria. There are 22 factors that were selected by only one state. There were 8 factors selected by 2-5 states, and 3 factors selected by more than

five states. Again, there appears to be minimal agreement among states as to which factors place children at-risk (see Table 5).

For the most part, states used a single factor approach to determining eligibility for children with environmental risk factors. However, there were two states who indicated that a child must have multiple risk factors in order to be eligible. It is not clear, however, how or why policymakers selected these particular combinations of multiple criteria. It appears to be based upon the previous eligibility criteria of the lead agency.

Further analysis also indicated that some of the factors or criteria included in the definitions are vague, and thus may be interpreted differently by different professionals. For example, one such criterion is "parental stress". It is left to professionals to determine: (a) if stress exists; (b) how much stress a parent must have; (c) what kind of stress exists; and (d) how to document parental stress in order for the child to be eligible. Is the stress of divorce judged the same as the stress of homelessness, lack of employment, etc? Another such example is the "lack of prenatal care". Does it mean no prenatal care, only one or two visits to the doctor during the prenatal period, or less than five visits?

What Process Is Used To Develop The Policy Concerning Definition Of Developmentally Delayed?

In the telephone survey, state respondents were asked to describe their policy development process including: (a) who drafted the policy (definition of developmentally delayed); (b) who provided input into the development of the policy; (c) who officially reviewed the policy; and

Table 5: Environmental Risk Factors Selected by States

Factors Selected by One State

high level of family disruption
lack of prenatal care
parent age/young
parental stress
disabled family member
inadequate child care
poor nutrition
lack of routine child care
wardship of state
homeless/transient family
home environment lacks physical resources
close occurring pregnancies
adolescent pregnancy
accident/environmental toxins
parent child interaction
adolescent parent
inability to perform parenting due to impairment in psychological functioning
limited opportunity to express adaptive behavior

Factors Selected by Two or More States

parental substance abuse (9)
parental retardation/mental illness (8)
substantiated abuse/neglect in home (6)
child abuse/disturbed parent/child relations (5)
Tjossem/broad definition (5)
low income/economic disability (3)
parent < 15 (3)
parental disability/health problem (2)
parental concern about development (2)
limited maternal/family support (2)
adoption (2)

Multiple Risk Factors Needed

parental substance abuse with poverty, abuse, and neglect (1)
teenage parent with poverty, abuse, neglect, and low birthweight (1)
3 or more of the following (1):
- low income/economic disability
- parents' lack of high school education
- sibling of handicapped child
- caretaker/18 or 19 at birth
- 3 or more children in family

*( ) number of states which included the factor

(d) who officially approved the policy. For most states, the policy development process has not been completed. Therefore, some of the respondents' answers were based on events which had already occurred, while other responses were based upon the respondents' prediction of what was likely to occur in future policy development steps. It will be interesting to study the policy development process over time to determine the accuracy of the predictions.

Drafting of the definition was most frequently undertaken by a committee or task force (29 states). In other instances the lead agency staff drafted a definition for the Interagency Coordinating Councils' (ICC) review and response. In five states the ICC as a whole, either was or will be, responsible for developing the draft. In four states the lead agency and the ICC developed the draft together. Two states will be using a consultant to assist with the development of the draft. Finally, as mentioned earlier, some states are using data from studies or pilot projects to facilitate the drafting of a definition.

In response to the question who will/did provide input into the development of the policy (definition), five groups were prominent:

the ICC as a whole (18 states);
service providers (15 states);
other key state agencies (13 states);
parents outside of the ICC (12 states); and
a task force or committee (13 states).

In many instances states used more than one source of input. Other groups cited but less frequently used to provide input were: lead agency; combination of ICC and lead agency decision-makers; consultants; advocacy groups; the public; pilot projects or studies; and legislative aides. When the respondents were asked who will/did

review the policy concerning the definition, three groups were mentioned most frequently:

the ICC;
the public; and
legal counsels.

Others also mentioned were other key state agencies, service providers, a committee, parents, pilot projects, advocacy groups, and lead agency administrators. Once again, in many states the policy will be reviewed by more than one group.

Four answers were prominent in response to the question who will approve the policy:

ICC (16 states);
legislature (12 states);
lead agency (11 states); and
governor (12 states).

Others mentioned for policy approval were: lead agency administrators, other key agencies, state boards (e.g. education or health). Fourteen states were unsure about who would provide final approval.

The answers to the questions concerning the policy development and approval process for the definition of developmentally delayed reveal both interesting and potentially critical information. First, there is considerable participation in the policy development process. Broad-based participation can lead to a policy that is more widely understood and accepted, thus decreasing many problems often encountered in the implementation phase (e.g. conflicts that arise among individuals, groups, or agencies which disagree with the policy). In addition to the benefits of broad-based participation, the inclusion of several individuals and groups in the review and approval process

often makes the policy development process more time-consuming. Therefore, there is the potential for missing the deadlines of the federal legislation. Second, many states are unsure of what form the final policy should take (e.g. legislation, executive order, board approval, interagency agreement, etc.) and thus who should approve it. Given the usual slow pace of the policy approval process within state government, once again it is possible that this issue could potentially cause some states to miss the federal deadlines.

Use Of Impact Research Or Evaluation Studies In Developing A Definition

There is a lack of research and recognized comprehensive models to meet the requirements of this legislation, especially concerning who should be served and how to identify them. This limitation has caused some states to develop studies or pilot projects to provide much needed information on the numbers and types of children who could potentially receive services. These efforts range from large systematic studies to small pilot projects. They also vary in the focus of the pilot project: handicapped only; at-risk only, or both handicapped and at-risk. The purpose, however, is the same - to provide data to assist policymakers in the policy development process.

Based upon the telephone survey, as well as information provided by Dr. Gray Garwood, there are 10 states using this approach. Some are using the pilot study to test out a draft definition, while others will collect data prior to developing a draft. The information gathered from these projects ought to be useful, not only to those ten states, but to many others, as well.

When Will The Definition Of Developmentally Delayed Be Completed?

At the time of the survey (6-7/88) all states plus the District of Columbia were asked to indicate when they projected that the definition would be completed and receive final approval. Three states indicated that the definition had already received final approval. Five states projected the definition would be finalized by October, 1988. Eight states projected January, 1989 for final approval. Six states projected approval by April, 1989; while seven projected final approval by July, 1989; and an additional eleven projected final approval by October, 1989. Thus, 38 states projected that their definitions will be finalized by October 1989, meeting the deadlines of PL 99-457. A few states projected final approval would occur in 1990 and several others were unsure just when their definition would be approved finally.

DISCUSSION AND CONCLUSIONS

Results of this study, which included an analysis of state policies and a telephone interview, indicated that many states have made a great deal of progress toward developing a policy regarding the definition of developmentally delayed. However, the results also indicated that many states had only partially completed this policy development process, while several states had not yet begun. Thus, while there has been progress in this critical policy development area, much remains to be done. Results also indicated that the definitions in many states are still undergoing review and revision. Therefore, those

children who currently are included may or may not be included when the policy is finally approved.

All 28 states have met the legal requirement to include developmentally delayed infants and toddlers, as well as those with established risk conditions (e.g. Down Syndrome). In most cases the states' definitions of these two groups closely mirror the language of PL 99-457, Part H. The definitions begin to vary greatly, however, when the eligibility criteria are examined and compared. It appears that children in one state may be eligible for services, but similar children in another state would not.

Also troubling is the finding that many states have selected to use criteria of percent delay or months delay when assessment instruments commonly in use are not designed to yield such scores. This also means that state policymakers have developed a policy that may be in conflict with the Code of Fair Testing Practices in Education (Joint Committee on Testing Practices, 1988) as well as the mandates of the Protection in Evaluation Procedures section of PL 94-142 regulations (Reg. 300. 350 - 300.534). These professional and federal standards state that instruments should be administered and scored in the same manner used to validate the test; if not, the norms do not apply.

An examination of state policies also revealed that the eligibility criteria selected by most states require the use of standardized assessment devices. Unfortunately, some types of delays or disabilities are difficult to detect and document using only standardized assessment instruments (Simeonsson & Bailey, 1989). State policymakers might be well-advised to include other approaches or

procedures to determine eligibility in addition to the use of standardized instruments.

At this point, it appears that several states have taken advantage of the opportunity to include at-risk infants and toddlers. However, there is currently considerable lack of agreement concerning which factors place a child at-risk. It is possible that if more states decide to include at-risk infants and toddlers the percentage of agreement may increase. The policy analysis also reveals that, despite literature to the contrary, there is a heavy reliance on the single factor approach to determining which children are at-risk for developing disabilities.

These current definitions fail to recognize the concepts of multiple and cumulative risk (Sameroff & Chandler, 1975; Sameroff, Seifer, Barocas, Zax, and Greenspan, 1987; Werner, 1986). The results of these studies indicate that as risk factors multiply, their combined effect is greater than the effect of any one of them alone. Thus, it is this combined effect of biological (e.g. neonatal seizures) and environmental factors (e.g. family instability) that leads to developmental delays and handicapping conditions (Kochanek, Kabacoff, & Lipsitt, 1987; Sameroff, Seifer, Barocas, Zax, & Greenspan, 1987). As state policymakers continue to develop and revise definitions and eligibility criteria, they may want to look more closely at the literature.

A related issue is cost. Many policymakers have been reluctant to include at-risk children in their state's definition because they fear the result will be costly. Use of the single factor approach is likely to include more children than the multiple factor approach. In addition, it remains to be seen whether states who are using impact data to help

develop their definitions will continue to study this issue longitudinally. Equally important is a systematic study of the long term cost and benefits in addition to those underway concerning the short term costs.

Based upon state responses it appears that there is a great deal of participation in the policy development process. While this is likely to lead to greater and more wide-spread acceptance of the policy, it is more time-consuming than having the policy developed by a few individuals in a single agency. Given that the development of this particular policy (definition of developmentally delayed) is so critical to the development of the other 13 components of a service system, progress in this area may affect policy development in the other areas. These results indicate that it may be difficult for some states to meet the 1989 deadline for having policies in place.

With the passage of PL 99-457, policymakers must confront the difficult task of defining the population to be served. Policymakers are also compelled to determine which factors render which children at-risk. In making these critical decisions, policymakers would be well-advised to go beyond the traditional use of previous policies or seeking examples from other states, and more carefully examine the literature concerning development and assessment of the handicapped and at-risk infant, as well as designing studies which will provide more scientific data for decision-making.

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